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June 13, 2003

Honorable Jo Anne Barnhart
Commissioner of the Social Security Administration
PO Box 17703
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Fax No. 410-966-2830

RE: Comments to the Advanced Notice of Proposed Rulemaking on Revised Criteria for the Mental Disorders Listings, 68 Fed. Reg. 12639 (Mar. 17, 2003)

Dear Commissioner Barnhart:

Community Legal Services ("CLS") appreciates having the opportunity to comment on the Advanced Notice of Proposed Rulemaking pertaining to the Mental Disorders Listings published at 68 Fed. Reg. 12639 (March 17, 2003). Attached please find our recommendations and general comments pertaining to the proposed rulemaking. In addition, we join in the comments of the Coalition of Citizens' with Disabilities (CCD) and those of the Joseph P. Kennedy, Jr. Foundation

We look forward to having additional opportunities to contribute to this process as the comment period closes and the arduous effort to update these Listings continues.

Thank you for your continued leadership in making the disability programs a very important part of the lives of many of our nation's citizens.

Very truly yours,

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Community Legal Services' Comments to the Advanced Notice of Proposed Rulemaking on Revised Criteria for the Mental Disorders Listings 68 Fed. Reg. 12639 (Mar. 17, 2003)

Community Legal Services, Inc. ("CLS") appreciates the opportunity to comment on the Advanced Notice of Proposed Rulemaking pertaining to the Mental Disorders Listings, 68 Fed. Reg. 12639 (Mar. 17, 2003). CLS is a public interest legal agency that provides individual representation in Title XVI Supplemental Security Income claims. Through its longstanding relationship with the Social Security Administration and its representation of individual clients, CLS has maintained a well-founded knowledge of both the agency's administrative procedures and how these are implemented on a regular basis by the state DDSs and OHA. Most recently, CLS played an integral role in the revisions of the Childhood Disability regulations in 2000.

CLS played a key role in the development of the recommendations related to the ANPRM that have been submitted separately by the Consortium of Citizens with Disabilities ("CCD") and the Joseph P. Kennedy, Jr., Foundation. Although we concur with all of those recommendations, we are submitting our own recommendations that in some places build on or enhance the recommendations made by these other groups, and in other places introduce additional recommendations that originate from our experiences as advocates who routinely represent claimants at administrative hearings and throughout the disability determination process.

Severity of Impairment and Functionality Are the Critical Elements of Any Revisions

The Mental Disorders Listings expect that a claimant with an impairment(s) that meets or equals the severity of the criteria described in a Listing would not be able to do gainful activity. However, many mental impairments not specifically identified in the Listings (e.g., eating disorders, post-traumatic stress disorder, learning disorder, attention deficit disorder, Alzheimer's or other dementias) may equal the Listings functional criteria. Some physical impairments may also be analyzed under the Mental Disorder Listings, when the physical disorder results in dysfunctions similar to those associated with mental impairments (e.g., sleep-related disorders, tumors, multiple sclerosis, traumatic brain injury, alzheimer's, and lupus). In general, a "medically equals" determination may capture some of these impairments, but this requires a medical opinion and in our experience is not being utilized with the proper frequency. Also, since SSA retains authority to make the medically equals determinations itself through its doctors, it doesn't ask treating physicians or even consultative examiners whether the person has an equivalent disorder.

Nevertheless, it is clear that the full and fair assessment of functional limitations is critical to most determinations of disability. For mental impairments, under the present system there are two points at which functioning is assessed, at Step 3 (the meets or equals phase) and at Step 5 (the residual functional capacity phase). If the claimant's functional limitations satisfy the enumerated paragraph B criteria in the Listings, and these result from a mental impairment, this should lead to a determination that the impairment(s) are severe enough to prevent gainful activity, either because the adjudicator determines the impairment meets or equals Listings criteria or the claimant's residual functional capacity ("RFC") precludes gainful activity.

Under the current procedures, fairly evaluating mental impairments at Step 3 relies on a thorough assessment of functioning principally in three areas that are not well-described in the regulations, and on a fourth area for "repeated episodes of decompensation" that is so constructed that it likely will not be relevant for most mental impairments, except for the most debilitating. That is to say, a person experiencing the frequency and severity of decompensating episodes currently required under the Listings paragraph B.4 criteria should be found to have an extreme[1] impairment and therefore disabled at Step 3 without recourse to any of the other three criteria under paragraph B.

Functional Criteria Revisions

Because of the emphasis on functional limitations within the Mental Disorder Listings, and to the ultimate determination of whether an adult is statutorily disabled, we recommend that

1) more specific functional descriptors are incorporated into the Introductory language of the Listings — that is, descriptors that encompass some of the functional areas presently evaluated in the Mental Impairment RFC; and

2) the "episodes of decompensation" be explicitly modified to include "episodes of deterioration" because this term encapsulates the characterization of this area of functioning described in the Introductory sections.

While we believe that SSA intends to include episodes of "deterioration," as confirmed by the description in the current Introduction section, use of the term "decompensation" creates

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1 The paragraph B.4 criterion requires "*repeated episodes of decompensation, each of extended duration*" which "means three episodes within 1 year, or an average of once every 4 months, each lasting for at least 2 weeks. If you have experienced more frequent episodes of shorter duration or less frequent episodes of longer duration, we must use judgment to determine if the duration and functional effects of the episodes are of equal severity and may be used to substitute for the listed finding in a determination of equivalence." If episodes of decompensation" were interpreted to require hospitalizations, or other very serious forms of professional intervention to assist the claimant to cope with deteriorating functioning, these manifestations of failure to cope without extraordinary support would render the claimant de facto unable to work. Because inability to work is the definition of disability under 42 U.S.C. § 1382c, satisfying this interpretation of paragraph B.4 would be de facto extreme limitation.

difficulty since it is used in the mental health profession to mean something more specific and more serious than SSA intends.

Paragraph B Functional Area Revisions

Because of the significance of functionality in the determination of disability, it is important for the descriptions of the functional areas to be clear and broad in scope. We recommend that SSA modify the Introductory section of the Mental Disorder Listings at 20 C.F.R. Part 404, Subpt. P, App, 1, 12.00C, where the descriptions of the four functional areas are outlined, in conjunction with cross-references to the regulations at 20 C.F.R. §§ 404.1520a & 416.920a (as well as all other relevant regulations), to incorporate the following characterizations of these functional areas:

1. *Activities of daily living ("ADLs")*

* ADLs particularly relevant are the ability to respond appropriately to change, to be aware of normal circumstances likely to cause frustration and to adapt accordingly, to travel in unfamiliar places or use public transportation without difficulty, and to set realistic goals or make plans independently of others and then carry these out.

* Marked limitation is assessed not by the specific number of different ADLs that are impaired but by the nature and degree of interference with functioning. If the individual is able to do a range of ADLs, but has serious difficulty performing them without supervision, or in a suitable manner, or on a consistent, routine basis, or without undue interruptions or distractions, then SSA may find this demonstrates marked limitation in ADLs.

2. Social functioning

* The abilities that are particularly relevant are the capacity to interact independently, appropriately, effectively, and on a sustained basis with other individuals. Functioning in this are includes having and using the skills necessary to get along with others, such as family members, friends, neighbors, clerks, landlords, or other public persons, even during periods of frustration or stress. Marked limitation may manifest in impaired interpersonal relationships, or social isolation, or difficulties communicating with others effectively, or problems in emotionally relating to others. The mere presence of "friends" should not disqualify a claimant who otherwise interacts only with difficulty with those who are not considered as "friends."

* Severity is judged on the ability to initiate social contacts with others, communicate clearly, interact and actively participate in groups, cooperate, show

consideration for others, exhibit and react with awareness of others' feelings, and social maturity. Functioning may involve the ability to interact appropriately with the general public, to ask questions or request assistance when appropriate, to accept instructions and respond positively to criticism from supervisors, and to get along with co-workers or peers without distracting them or exhibiting behavioral disturbances.

3. *Concentration, persistence, or pace*

* Ability to sustain focused attention and concentration sufficiently long to permit the timely and appropriate completion of tasks. Functioning includes ability to maintain attention and concentration for prolonged periods, to perform within a schedule, to maintain regular attendance, and be punctual within customary work-setting tolerances, to sustain an ordinary routine without additional supervision, to work in coordination with others and to continue to work with others nearby without being distracted by them, to make simple decisions and show basic judgment, to complete a normal day or week of activity without interruptions from symptoms, and to perform at a consistent pace without needing an unreasonable number or length of rest periods.

* Limitations may be assessed on mental status examination, as monitored by tasks such as having serial sevens or serial threes. On IQ or other psychometric testing, ability to concentrate may be measured through tasks requiring short-term memory or tasks that must be completed within established time limits. Evaluations of functioning in this area should be more than reports from how the claimant functioned at a CE, where the claimant is in a time-limited and more structured situation and can be expected to be more "presentable," focused, and oriented to the tasks presented by the CE.

4. *Episodes of decompensation or deterioration*

* This area assesses episodes of deterioration of the individual's existing positive coping strategies, leading to an exacerbation of signs or symptoms and the need for intervention that may require an increase in medication, more frequent or intensive counseling sessions, or, in extreme cases, psychiatric hospitalization.

* Episodes of decompensation or deterioration may be inferred from records showing significant alteration in medication, increased or more intensive therapy or more frequent sessions, or from evidence or documentation of the need for more intensive support; or other relevant information in the record about the existence, severity, and duration of the episode.

* The need for more structured setting (e.g., psychiatric hospitalization, placement

in a day program or halfway house, or a highly structured and directing household) may demonstrate an extreme limitation in functioning.

Role of Substance Abuse, Addiction, and Alcoholism

SSA rules disallow a determination of disability where drug abuse or alcoholism is a significant factor in the etiology of the individual's mental impairment. Essentially, adjudicators must consider how the claimant's mental impairment would be affected if the substance abuse or alcohol use were discontinued. The process for determining materiality in this process needs to be clarified, and the co-morbid incidence of mental impairment and substance use needs to be recognized and properly evaluated. We recommend that the following language is incorporated into a separate section in the Introduction addressing the materiality role in determinations made where DA & A is an issue:

* For some individuals with mental impairments, the use of substances to alleviate unwanted symptoms may make the determination of materiality more complicated.

* Long-term abuse of alcohol or substances may cause neurological difficulties or loss of other physical or cognitive functioning that may be irreparable.

* It is critical that decisions about whether substance abuse contributes substantially to the severity of the individual's current mental impairment are derived from a full and medically sound consideration of the nature of the substance use and the impact of substance use on any functional limitations imposed by the individual's other mental impairment(s).

* Sometimes the substance abuse may be symptom of a more severe underlying mental impairment and adjudicators must be alert to fairly and completely assess the severity of all of the individual's impairments before reaching any conclusion about the materiality of the substance use.

Other Factors SSA Must Consider

We endorse the recommendations submitted separately by the CCD and the Kennedy Foundation and make the following additional recommendations:

Evaluation of the severity of mental impairments is particularly difficult for individuals who have histories of deteriorating responses to their impairments manifested by infrequent psychiatric hospitalization (or none) but prolonged outpatient care with supportive therapy and medication and dosage changes. Such individuals may have their lives structured in such a way so as to minimize their stress and reduce their symptoms and signs. If self-imposed or externally imposed "structure" successfully prevents the need for more intensive psychiatric care, it is

possible that claimants may be much more impaired than their symptoms or signs indicate.

1. *Effects of structured setting (modifying section F of the Introduction)*

* Overt symptomatology may be controlled or attenuated by psychosocial factors such as a structured or supportive setting and signs, symptoms, and functional limitations may worsen outside this type of setting. Even if the individual is able to function adequately in the structured treatment program or supportive work setting, adjudicators must consider how the claimant functions in other settings and whether the claimant would continue to function in the typical work setting at an adequate level without the structured or supportive setting.

* If symptoms or signs are controlled or reduced by medication and/or therapy, adjudicators must consider whether the claimant appears higher functioing because of reliance on the assistance from others (professional or lay) and whether the claimant has made significant adjustments in environment so as to minimize stress or frustrations. These type of supports are usually unavailable in the typical work setting.

2. *Assessing the impact of stress and normal frustrations (adding a new section to the Introduction tracking SSR 85-15).*

- ☐ It is not unusual that some individuals with mental impairments have significant difficulty accommodating to the demands of work.

- ☐ Individuals with mental impairments often adopt a highly restricted and/or inflexible lifestyle within which they appear to function well. Good mental health services and care may enable chronic patients to function adequately in the community by lowering psychological pressures, by medication, and by support from services such as outpatient facilities, day care programs, social work interventions, and similar assistance. The reaction to the demands of typical work stress is highly individualized, and mental impairments are characterized by adverse responses to seemingly trivial circumstances, as frequently arise in the work environment.

- ☐ Some individuals may cease to function effectively when facing such routine demands as getting to work regularly, having their performance supervised, and remaining in the workplace for a full day. These claimants may have difficulty meeting the requirement of even so-called "low stress" work.

3. *Noncompliance with medication or other treatment (modifying section G of the Introduction, tracking SSR 96-7p language).*

- ☐ For many severely impaired claimants their prescribed medications may be as

intolerable to them as the signs or symptoms of their mental impairment itself. Furthermore, for some claimants it is in the nature of their impairment not to follow prescribed treatment not for oppositional or defiant reasons but because of the symptomatology of their mental impairment.

- It is crucial that whenever noncompliance is an issue that all adjudicators understand and implement the assessment procedures outlined in Social Security Ruling 96-7p before concluding that failure to follow prescribed treatment may exclude a claimant without further justification.

Documentation (modifying section 12.00D)

Because diagnosing, treating, and managing life with a mental impairment usually involves verbal and behavioral communications with mental health professionals, SSA should consider self-reports and the reports of others made to mental health professionals to be crucial evidence of the severity of impairments when the mental health professional relies on this information to diagnose or provide treatment recommendations. This recognizes the medical norm that the "medically acceptable clinical and laboratory diagnostic techniques" in the mental health world primarily are impressionistic observations made by a professional during an interview.

Most claimants with mental impairments are likely to obtain treatment principally from social workers, family therapists, mental health technicians, physicians' assistants, nurse clinicians, or lay counselors. Even the most seriously impaired will interact with a psychiatrist or psychologist infrequently or irregularly. For example, in most partial hospitalization programs, the psychiatrists rotate through units and meet with most of the clients for "medication reviews," not therapy. It is unfair under these conditions to require of claimants that they produce routine and comprehensive treatment records from a psychiatrist or psychologist when it is much more common for the professionals who provide most of the treatment, and therefore generate most of the documentation, are not currently recognized by SSA as "medical sources."

We recommend that except under the rarest of circumstances, SSA should accept as medical evidence documentation from the other professionals who provide the primary care for most claimants with mental impairments. Reports from these non-physicians regarding the severity of impairment, assessment of functional limitations, and treatment progress should be accepted by SSA as "medical evidence" because this is how this evidence is construed by third party insurers and indeed by state regulators of mental health care. This is because most treatment in today's mental health world is provided as part of a team, of which a psychiatrist may be the authorized "physician" whose approval for treatment is all that is required for reimbursement purposes, but whose role in the management of mental health treatment often is more circumscribed than for other attending physicians.

Modify Sub-paragraphs 1 and 2: Sources of evidence

We endorse the recommendations submitted separately by the CCD and the Kennedy Foundation and further recommend that:

* SSA relies on evidence from acceptable medical sources, who are defined as physicians, psychiatrists, and psychologists for adults, and may include speech and language pathologists, or certified school psychologists, for children.

* Most claimants with mental impairments do not have prolonged interactions with psychiatrists or psychologists but rather receive regular, ongoing attention from other professionals such as social workers, mental health technicians, counselors. Claimants are disadvantaged when these other professionals produce documentation of ongoing treatment (including biopsychosocial assessments, treatment plans, progress notes) that is more thorough and comprehensive than the psychiatric notes but not weighed accordingly by SSA's adjudicators.

* "Other sources" include many of the primary sources of treatment for individuals with low income who have mental impairments. These may include some professionals who might be considered to be "treating sources" under different criteria: e.g., nurse practitioners and physician's assistants, therapists, psychiatric social workers, mental health workers, and educational or rehabilitation personnel.

* Many low income individuals with mental impairments are seen infrequently by psychologists or psychiatrists and usually only interact with these medical professionals for a review of medications. Other professionals are qualified, trained, and often licensed under state law to recognize and provide the primary treatment for people with mental impairments and often are the most important source of evidence about claimants.

* Nonphysician sources (e.g., therapists, social workers, counselors) may interact with the claimant more frequently than a treating psychiatrist and may have a more thorough knowledge of the limitations caused by the claimant's impairments.

* SSA also should obtain information, particularly about the individual's functioning, from non-medical sources, such as family members and others who know the individual (like neighbors, relatives, former co-workers), to supplement the record in order to establish the consistency of the medical evidence and longitudinal nature of impairment severity.

* Other sources of information about functioning include, but are not limited to, records from work evaluations, rehabilitation progress notes, and, for younger

adults, records from school, school-related activities, and vocational education programs

Proposed Listings

We endorse the recommendations submitted separately by the CCD and also recommend that SSA add the following diagnostic categories to the Listings. Further specifics on these Listings additions are contained in the recommendations by the CCD.

Post-Traumatic Stress Disorder ("PTSD") criteria to augment the current Listings 12.06 and 112.06.

Eating disorders to become a new Listing.

Developmental Learning Disorder to become a new Listing. The National Research Council ("NRC") recommended adding a Listing for the differential diagnoses that mimic the signs and symptoms of mental retardation; this Listing would have criteria to distinguish these diagnostic categories from the mental retardation Listing. We recommend a Listing for "Developmental Learning Disorder" (at Listings 12.13 & 112.13) that encapsulates the specific Learning Disorders ("LD"), Borderline Intellectual Functioning ("BIF"), and other cognitive or language and communication disorders. These are encompassed by the NRC's "differential diagnoses" for excluding mental retardation when assessment through standardized tests shows cognitive or language processing difficulties not explained by mental retardation. This Listing would reference SSR 98-1p and could incorporate language from this Ruling, along with specific paragraph A criteria for the adult Listing that would capture the younger adults who transition to adulthood and who, in the absence of an additional physical impairment, presently have no method for being found functionally unable to work under Step 5.

Although in most instances LD alone (or BIF or speech/language disorder) probably would not be disabling, in the absence of a Listing the assessment of these "differential diagnoses" is relegated to a determination whether the claimant meets the requirements of the Listing for Mental Retardation. As the NRC points out,[2] this unfairly limits claimants with these impairments to having their claim decided using only the one Listing as guide which in most instances would be the incorrect Listing to apply. Like others currently within the Mental Disorders Listings, the proposed Listing would require that the impairment or combination of impairments impose marked limitations in 2 of the paragraph B criteria, so there is not likely to be many claimants who will satisfy that requirement with LD alone. However, the benefits of adding this Listing, for both SSA and claimants, is that adjudicators will be compelled to fulfill the requirement to assess these impairments under the "Mental Disorders Listings," not just the Listing for mental retardation, and will not improperly discount the effects of any of these impairments when it is co-morbid with another mental or physical impairment.

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2 See National Research Council, Mental Retardation: Determining Eligibility for Social Security Benefits 263-64, 275 (2002).

18 Year Olds / Section 301 (special education, vocational training, and CDRs)

In our experience, when a claimant with a mental impairment is still in special education or engaged in supportive work or other vocational training program, some adjudicators conclude that the 18 year old claimant (or disabled youngster facing a CDR) has no functional deficiencies merely because he or she participates in one or more of these supportive programs. This especially is problematic for CDRs and redeterminations of 18 year olds, many of whom may have been eligible since infancy. Some adjudicators conclude that participation in special education or a supported work setting means that a claimant with a mental impairment can have no significant limitations in social functioning or in concentration, persistence, or pace merely because the claimant is engaged in productive activities.

Because there is no objective vocational assessment included in the decision making process at any stage, it is apparent that being active in one of these supportive programs may improperly be interpreted to mean that the claimant is not disabled without a full appreciation for the realities of the claimant's need for these supports. Should the claimant's impairments not meet or equal listings-level severity, a thorough vocational assessment could lead to a finding of disabled under Step 5 if it confirms that the claimant is functionally unable to learn to do unskilled work. At the present time, however, there is a presumption that 18 year olds who can follow simple directions cannot be disabled, regardless of the severity of their mental impairment. Social Security Ruling 96-9p specifically addresses some of the issues raised by the inadequacies of the present Step 5 in assessing functional limitations associated with mental impairments, but this Ruling requires an additional physical impairment and does not explain how to assess the functional limitations when only a mental impairment is at issue.

Therefore, we recommend that SSA

1) clarify the appropriate circumstances that require a Section 301 likelihood determination; that is, when a young person is engaged in a vocational training program which is likely to lead to gainful employment and eventual abandonment of the need for SSI.

2) amend the regulations (and support any concomitant statutory amendment that might be required) to include within these Section 301 protections young persons whose participation in special education is permitted by the IDEA until age 22.

3) prior to making a disability determination SSA should require comprehensive vocational assessments for young persons facing an initial CDR after turning 18 and for all "younger" claimants who are without a legitimate work history.

4) provide specific instructions that any inference that there are few or

no functional deficiencies must be based on a proper assessment of all of the evidence in the record and not merely deduced from a claimant's participation in one or more of the kinds of supportive programs in which claimants with mental impairments might engage.

5) SSA adopt a new Listing that encompasses the differential diagnoses for younger adults who do not have mental retardation but manifest cognitive or adaptive functional limitations. See the proposed Listing "Developmental Learning Disorder" above.

Change the Rules to Further Encourage Work Efforts by People with Mental Impairments

Individuals with mental illness frequently cannot take advantage of the policies developed in both law and regulations in recent years that encourage people with disabilities to work. Many individuals with mental illness find that their symptoms can be controlled with medication and other treatment. However, when they get to the point where they are able to work, at least on a part time basis, they face immediate disqualification and, if they receive SSI in a § 1634 state, often lose their eligibility for Medicaid. This is because of the SSA policy that as soon as their work activity exceeds the SGA level (currently $800 per month) they are no longer considered disabled. Thus, they are not eligible for the special treatment provided in § 1619 that maintains Medicaid status, as well as other policies meant to encourage self-sufficiency, putting people with mental illness at a disadvantage when compared to the treatment afforded people with physical disabilities. Ironically, the loss of Medicaid often endangers the progress they have made, since Medicaid is the source of the treatment, especially pharmacological treatment, that has restored a level of function.

SSA should alter its policy to encourage work attempts and allow those struggling to overcome mental illness to pursue their potential, by considering those diagnosed with a mental disability to be disabled, even when their symptoms are managed by medication or other treatment. While symptoms can be controlled with medication, professionals in the mental health field will attest to the fact that individuals with mental illness still have a disability and are in danger of deteriorating or even decompensating if their treatment and medication are disrupted. In the long run, the Congressional goal of rehabilitation is served by supporting people as they attempt to work rather than taking away all supports as soon as they make halting steps toward self-sufficiency.

Conclusion

We applaud the Commissioner for taking the unusual step of publishing an ANPRM and getting comment from the public earlier in the development stage. We urge the Commissioner to continue this policy of openness and consult with commenters and other members of the public as this regulatory change makes its way through the rule making process. We are ready to provide the Commissioner with the benefit of any expertise that we may have developed over the

years in the course of our representation of thousands of claimants.

Respectfully submitted,

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